Fifteen minute consultation: Modern day art and science of managing Cerebral Palsy.

Jill Cadwgan, Jane Goodwin and Charlie Fairhurst

Abstract

Whilst there remains limited intervention to address the damage to the developing brain, current multidisciplinary management of cerebral palsy (CP) needs to minimise the impact of secondary musculoskeletal complications. A focus on comorbidities, to maximize function for activity and participation by supporting the child and family in their environment is required. Comprehensive clinical guidance was published by NICE earlier this year. This article aims to provide a practical clinical approach to the child and family, based on:

- 1) **Art:** Empathy, listening and weighing up the clinical picture of the child and family in context; diagnosis, the need for support and space, and care co-ordination at the right time.
- 2) **Science:** the current science in CP care is rapidly expanding in terms of plasticity, pathophysiology, functional assessments, and treatments.

Introduction

Definition and epidemiology

“Cerebral palsy (CP) describes a group of permanent disorders of movement and posture, causing activity limitation that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour; by epilepsy and by secondary musculoskeletal problems.”

This current definition of CP¹ recognizes the importance of the International Classification of Functioning Disability and Health: Children and Youth Version (ICF-CY²); to facilitate our understanding of the impact of CP on the child and family, encapsulating functional problems. (Figure 1)

The overall prevalence of CP in developed countries is 2–3 per 1000 live births, though in susceptible premature infants (<28 weeks gestation) it rises to 100 per 1000³.

Pathophysiology

Rapid central nervous system growth occurs in-utero, until 5 months postnatally. At this time the brain is susceptible to malformation, infection, damage and disruption of its emerging blood supply. The “watershed areas” are most susceptible to damage: in the pre-natal brain the ‘periventricular zone’ of the motor cortex, at term the subcortical white matter. At term hypoxic damage also occurs in the cells with the highest metabolic need: the basal ganglia, the ‘locomotor driving system’ of our motor control, where reflex patterns of movement are unconsciously coordinated.⁴

Fluid motor patterns initiated by desire and anticipation of function, are modified by inputs such as peripheral sensory interaction, vision and balance (equilibrium and adaptive systems). Intracerebral reflex loops organise the descending upper motor control of the peripheral lower motor neurons via, among others, the corticospinal tracts. When this

complex motor system is impaired, the fluidity of control breaks down, leading to the ‘non-progressive movement disorder’⁴.

There is a caveat to the “non-progressive” definition. Following insult there is significant potential for cortico-spinal tract re-organisation: ‘neuroplasticity’. This may be beneficial, or may cause further impairment⁵.

Classification of CP

Motor pattern and distribution

The distribution and motor pattern observed are associated with the site of the underlying primary pathophysiology, (Table 1)

The Surveillance of Cerebral Palsy in Europe (SCPE) classification uses the terms ‘unilateral’ or ‘bilateral’ and focuses on the type of motor disorder seen ⁶. The limitation of this classification is early delineation between spasticity and dystonia.

- Cortico-spinal tract damage results in the “upper motor neurone syndrome”. This includes disinhibition of the spinal reflex arc and muscle over activation:
spasticity -velocity dependent hypertonia⁴.
- Damage to the basal ganglia leads to patterns of sustained muscle contraction of usually antagonistic muscle pairs causing abnormal postures or joint position:
dystonia and involuntary movements which include chorea and athetosis:
dyskinesia⁴.

Many children with CP have a mixed pattern of spasticity and dystonia⁷, with other features of the upper motor neurone syndrome: weakness, poor selective motor control, sensory inattention, difficulties with motor planning, and non-neurological tissue changes.

Severity

The gross motor functional classification system (GMFCS⁸) (Figure 2) is a reliable prognostic indicator of motor function. Other developmental functional classification systems

have also been developed. (Figure 1)

Clinical care

The clinician needs a clear understanding of the underlying aetiology and pathophysiology. Further, they need be able to communicate this effectively to the family and other professionals working with the child, understand the child and family in context: how the diagnosis has affected them, and how management of the condition will impact on them throughout the life course.

Identification, diagnosis and information sharing

Parents report dissatisfaction with the disclosure of a CP diagnosis. Many children referred to tertiary clinics have been labelled with cerebral palsy, but the family may have not fully understood this description. They often have questions regarding motor function (will their child walk?), communication potential, educational provision, medical interventions, participation, and family life ⁹.

Review of the potential causation helps the clinician to answer the many questions, and also support the family emotionally, assessing understanding of information previously shared ¹⁰.

Although cranial imaging is often performed in the neonatal period, repeat imaging at 2 years is more reliable due to myelination and grey matter maturation. If there is diagnostic uncertainty (i.e. mismatch of history and clinical presentation, signs of neurological regression) MRI, alongside metabolic and genetic investigations should be pursued. Otherwise, MRI alone is unlikely to change CP management ¹¹.

Clinical examination should focus on motor function, distribution and nature of motor signs; but must also include assessment of other development, including functional assessments. Cognition, language (receptive and expressive; speech or alternative communication), and associated sensory impairments may have more influence on

participation in community, school, and family activities than motor function^{4,11}.

Never underestimate parent understanding, they are the expert on their child ⁹.

Explain how the child's current clinical signs match the background history. Show scans and explain how the pattern of cerebral insult directly relates to their child's presentation, and how this may help to predict prognosis ¹².

Management of motor impairments

The mainstay of multi-disciplinary management of CP is therapy, equipment and support. The goals of therapies (including physiotherapy, occupational therapy, and speech therapy) are:

- Promoting development according to potential.
- Providing equipment or support to facilitate participation in home and school.
- Detection and prevention of secondary complications.

There are a vast array of therapy interventions, orthoses and equipment that may be used, with a wide variation in evidence base. Therapists rely on parent and other carer delivered interventions, so support must be given to training them ¹³.

Medical interventions

The choice of medication is considered according to the predominant motor pattern. These include systemic oral medications or focal treatment with botulinum toxin ¹⁴. Principles of treatment are: start low, escalate slowly, assess response, and withdraw if evidence of adverse effects or no benefit ^{4,11}. (Table 2)

Treatment with botulinum toxin should be carefully considered, with clinical assessment by a multi-disciplinary team with expertise ¹⁴. Goals must be identified and post treatment re-assessment is essential. Communication with local teams should ensure adjunctive therapy intervention or orthoses are well co-ordinated.

Surgical Interventions

Orthopaedic

Referral pathways between community and tertiary multi-disciplinary teams and surgeons with expertise in CP should be clear. Proposed UK-wide implementation of the Cerebral Palsy Integrated Pathways Scotland (CPIPS)¹⁵ hip surveillance programme aims to facilitate this. Monitoring of motor progress, growth and physical parameters is key. The focus is on surveillance: preventative surgical intervention for hip subluxation and early identification of neuromuscular scoliosis. Guided growth for knee flexion contractures, epiphysiodesis for limb length discrepancy and muscle lengthening remain common procedures.

Neurosurgical approaches

Intrathecal baclofen pump insertion (ITB)¹⁶, Selective Dorsal Rhizotomy (SDR)¹⁷ and deep brain stimulation (DBS)¹⁸ are all available at highly specialist centres in the UK. Detailed assessment and patient selection is essential, and there needs to be clear communication between the specialist centre and all other multi-disciplinary teams involved with the child and family, to ensure close monitoring and follow up is maintained.

Other treatments: keeping up with knowledge

As no “cure” is available multiple other treatments are considered. Complimentary therapies, off label medications, and stem cell therapies are often discussed by families guided by information on the internet.

Understandably, parents are likely to want to try anything that may improve their child’s quality of life. This leaves them vulnerable to interventions that may be costly, not improve their child’s functioning, and/or cause harm. It is important that clinicians show respect for the parents’ knowledge and research, but feel confident to guide them towards accurate and honest information regarding realistic expectations ⁹.

Medical management of general health and other co-morbidities

Co-morbidities are significant drivers of poor tone and motor control. Sleep deprivation, distress due to pain or feeding difficulties are often the most disruptive factors for children and families. Empathy and management of these, alongside treatment of the other frequent co-morbidities e.g., epilepsy, GI dysmotility (gastro-oesophageal reflux, delayed gastric emptying, constipation) recurrent respiratory infection, sialorrhoea and orthopaedic complications is paramount. Often if these are appropriately managed, further medications or management of tone may not be required.^{4,11}

Educational support

Accurate and timely identification of the child's full developmental profile is essential to support appropriate educational provision. Implementation of the Education, Health and Care Plan (EHCP) facilitates mandated annual reviews and ensures the child and family views are heard. Practical considerations include cognitive, communication and sensory issues, and how the child's needs may be met in the context of motor impairment. Therapy programmes are important, but delivery of these should be balanced with educational priorities.

Social and leisure support

The most important thing for a child is to participate in and to enjoy activities. "Put the fun into function!" Helping participation by signposting to appropriate, activities, organisations, social care, charities and support is a significant role of the clinician, and is highly valued by families.

Life course approach

Management of cerebral palsy goes beyond childhood. That is, supporting children and their families throughout adolescence, and into becoming a participating adult, whatever their motor function and other developmental or health needs. Recently published NICE CP¹¹ guidance and EHCP¹⁹ planning is now extended to age 25 years. There is current paediatric input into the development of adult CP guidance. There needs to be development of adult

physicians with CP expertise in order to have appropriate services to “transition” to.

Conclusion

The modern day CP clinician should be a grounded general paediatrician who considers the child in the context of their family and environment, and supports them to become a participating adult. There is little complicated with respect to CP management, rather a range of general paediatric presentations in the context of a distraction of an underlying neurodevelopmental diagnosis.

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Tables and Figures

Table 1: Clinical presentations of cerebral palsies according to cerebral insult

Clinical motor presentation	Aetiology	Timing	Pathophysiology	Clinical Features
Hemiplegia Spasticity Dystonia or mixed.	Vascular insult (most frequently)	Pre-natal Perinatal Postnatal	Grey or white matter in arterial territory	Dependent on site and extent of vascular lesion: variable Epilepsy, learning, sensory impairment
Bilateral – predominantly lower limb spasticity	Prematurity	Pre-natal (3 rd trimester) IVH	Periventricular white matter	Cognition may be well preserved, epilepsy unlikely
Bilateral - predominantly spasticity	Congenital infection	Pre-natal	Grey and white matter	Cognitive impairment, epilepsy +/- other sensory impairments
Bilateral – predominantly dystonia and dyskinesia	Mild-moderate hypoxic ischaemic encephalopathy	Perinatal Postnatal	Basal ganglia (deep grey matter)	Cognition often well preserved, epilepsy unlikely
Bilateral – mixed spasticity, dystonia and other associated sensory	Profound hypoxic ischemic encephalopathy Peri or postnatal infection	Perinatal Postnatal	Grey and white matter	Severe motor impairment Bulbar dysfunction Sensory abnormalities Cognitive impairment and epilepsy

Table 2: Summary of muscle relaxants and antidystonic medicines:

Green = Frequently used as First Line; Amber = Used as second line; recommend specialist input; Red = Caution to use or rarely used in children

	Background and effect	Side effect	Dose
Muscle relaxant			
Baclofen	The commonest drug for adult and childhood hypertonia, used since the 1970s It works on the pre and postsynaptic GABA _B receptors of the spine to reduce excitation of the spinal reflex arc	It has difficulty crossing the blood–brain barrier and therefore high-peripheral doses of oral medicine are necessary for effect As such, it has a narrow therapeutic window before significant side effects of truncal hypotonia, sedation and increased seizure propensity are seen	Start 5 mg, three times a day, halved in very small children Max 2-3 mg/kg/day. Increased slowly to effect or side effect Occasional escalation higher with specialist supervision.
Tizanidine	Used increasingly frequently in the adult population This central α2-noradrenergic agonist is generally better tolerated than baclofen in adults	There is limited experience of its use in children Sedation, hypotension, agitation, depression and gastrointestinal problems are the main side effects	Uncertain start 1mg twice daily <10 years 2mg od >10 years Max 0.05 mg/kg/day 2mg three times a day >12 years
Diazepam	Other benzodiazepines work at the spinal GABA level by increasing presynaptic inhibition. They are extremely effective, especially in short-term use if emergency muscle relaxation is needed or sleep disturbed	Highly sedating and tolerance is easily developed Benzodiazepine withdrawal syndrome is a significant concern with long-term use, especially in the very young	Start 0.25 mg/kg twice daily Max Infant 2.5 mg twice daily Child 5 mg twice daily >12 years 10 mg twice daily
Dantrolene	Works at the muscle level by inhibiting calcium release from the sarcoplasmic reticulum	It causes global weakness and rarely, though <i>catastrophically</i> , <i>liver failure in around 1% of patients</i>	Start 0.5 mg/kg twice daily for 4 days, increase to three times a day then four times a day Max 2mg/kg four times a day or 100 mg four times a day
Antidystonic medicine			
Trihexyphenidyl	Probably the antidystonic medicine with the greatest therapeutic benefit This anticholinergic agent works at the level of the basal ganglia	Side effects come from its mode of action and include disorientation, gastrointestinal disturbances (especially constipation), urinary retention and xerostomia (excessively dry mouth)	Start 0.5, 1 or 2 mg twice daily, increase weekly to twice daily, then three times a day, then 0.5 mg – 2 mg/week Max 1 mg/kg/day Exceptionally high doses are often necessary, up to 1.6 mg/kg/day
LevoDopa plus Cocareldopa	If there is any possible doubt about diagnosis from history and/or neuroimaging, then a trial of LevoDopa should be given. Rarely a DOPA responsive dystonia can mimic CP with extraordinary benefits for the individual if treated early	It is given with a peripheral inhibitor – Co Careldopa (Sinemet, Madopar) to minimise side effects of nausea, insomnia and increased chorea Laevo:Cocarel – 4:1 ration at low dose, 10:1 ratio at high dose Check liver function 6 monthly	Start 1–2 mg/kg/day LDopa in —four – six doses Max Increase every 2–3 days to max 10 mg/kg/day
Clonidine	α2 adrenergic agonist Increasingly used for dystonia, especially where there is distress/agitation. Highly useful in peri-operative management. Can be used as “rescue” or regular in acute or community	Hypotension, sedation, dry mouth Tolerance and escalation of doses often required	Test dose (3microgram/kg) if commencing for acute symptoms advised on ward (BP monitoring) Can gradually escalate lower dose in community. Start 1microgram/kg nocte Max Can be used up to 4 hourly if required 3microgram/kg. Occasional escalation higher with specialist supervision.
Gabapentin	GABA- analogue, modulates GABA biosynthesis, but activity also through voltage gated Ca ²⁺ channels Increasing evidence of benefit in dystonia especially if associated with choreoathetosis	Sedation, fatigue, dizziness, occasional irritability.	Start 5mg/kg/day (3 divided doses) Max Licensed – 50mg/kg/day (6-12yrs) BNF -70mg/kg/day
Tetrabenazine	Rarely used in paediatric practice. Dopamine depletors, prevent neurotransmitter degradation	Akathesia, depression and other mood disorders, agitation	Start 12.5 mg increase slowly to max Max 100 mg/day

Note. CP = cerebral palsy, DOPA = dihydroxyphenylalanine, GABA = γ-amino butyric acid.

Figure 1: International Classification of Functioning Disability and Health: Children and Youth Version (ICF-CY) – related to CP

Note. Disability is not solely a medical impairment; it is also a social construct. Therefore, context is an important influence. The ICF-CY offers a holistic conceptual framework and common terminology for recording problems involving functions and structures of the body, activity limitations and participation restrictions, and environmental factors important for children and youth.

GMFCS = Gross Motor Functional Classification System
 MACS = Manual Ability Classification System
 EDACS = Eating and Drinking Functional Classification System
 CFCS = Communication Functional Classification System
 VFCS = Visual Functional Classification System

Figure 2: Gross Motor Functional Classification System (GMFCS)

GMFCS Level I

Youth walk at home, school, outdoors and in the community. Youth are able to climb curbs and stairs without physical assistance or a railing. They perform gross motor skills such as running and jumping but speed, balance and coordination are limited.

GMFCS Level II

Youth walk in most settings but environmental factors and personal choice influence mobility choices. At school or work they may require a hand held mobility device for safety and climb stairs holding onto a railing. Outdoors and in the community youth may use wheeled mobility when traveling long distances.

GMFCS Level III

Youth are capable of walking using a hand-held mobility device. Youth may climb stairs holding onto a railing with supervision or assistance. At school they may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community youth are transported in a wheelchair or use powered mobility.

GMFCS Level IV

Youth use wheeled mobility in most settings. Physical assistance of 1-2 people is required for transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility or a body support walker when positioned. They may operate a powered chair, otherwise are transported in a manual wheelchair.

GMFCS Level V

Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements. Self-mobility is severely limited, even with the use of assistive technology.

Table 3: Summary of Neurosurgical Interventions for CP

Neurosurgical intervention	Appropriate Patient Selection (evidence)			Complications and limitations
	Motor severity	Type of Movement Disorder		
		Spasticity	Dystonia	
			Dyskinesia	
Intrathecal Baclofen Pump (ITB)	GMFCS IV-V	YES	YES	Frequent refills required Weakness Sudden withdrawal – status dystonicus <ul style="list-style-type: none">• Catheter breakage• Pump failure Infection Skin breakdown
Selective Dorsal Rhizotomy (SDR)	GMFCS II-III	YES	NO	Weakness Poor selective motor control Sensory disturbance Long-term functional mobility may not be improved Irreversible
Deep Brain Stimulation (DBS)	GMFCS IV-V	NO	YES	Infection Evidence base limited in secondary dystonia (CP) Irreversible (although may be switched off)

Table 4: Current Challenges for CP care- and how we may overcome them.

Challenges	Opportunities	Top tips
<i>Diagnosis</i>		
Parents still report anxiety and dissatisfaction with the diagnostic journey	<p>NICE CP Guidance</p> <p>Recommendations for follow up of “high risk infants”</p> <p>NICE CP Quality Standards</p>	<p>Power of open discussion with families: honest sharing of basic pathology and science, highlighting what we do and do not know.</p> <p>Human kindness and empathy is essential.</p>
Transitional care and care of adults with cerebral palsy	<p>NICE CP Guidance for adults has paediatric representation on the guidelines committee.</p> <p>NICE CP guidelines now for 0-25 years.</p>	
<i>Paucity of clinical evidence</i>		
Limited evidence base for almost all interventions (therapeutic, medical and surgical) for children with CP.	Real drive in literature – and by professionals and families to search and generate good quality evidence.	<p>Don’t miss what is already known: it takes 15-20 years from lab to clinical intervention: now is time to move research and change attitudes:</p> <ul style="list-style-type: none"> Research needs to shift to ICY-CY(2001) rather than focusing on body structure. It is important to fund research into meaningful outcomes for young people (e.g., activity and participation). CST reorganisation and pathophysiology research shows exciting avenues for early intervention.
Generation of evidence challenging in heterogenous population, with multiple confounders, limited outcome measures, and need for large scale longitudinal data for traditional body structure outcomes.	Honest and open discussion regarding what we do and don’t know. Novak article in 2013 (although limitations) gave comprehensive review of evidence state.	<p>Engaging young people with CP and their parents in research is essential to develop meaningful outcomes for families.</p> <ul style="list-style-type: none"> Benefit of qualitative or mixed methods research should be acknowledged.
Multiple interventions: old: “inherited practice” and an exponential number of new approaches.	Recognition and priority setting for research in paediatric neurodisability are focussing on outcomes meaning to children and families. (BACD- SRG* James Lind Alliance)	
<i>The internet and access to information</i>		
Parents may be susceptible to overestimating the value of low quality information and advice, leaving them vulnerable to interventions that may be costly, not improve	The internet can be empowering and beneficial for accessing support.	<p>Show respect for the parents’ knowledge and research but feel confident to guide them towards accurate and honest information regarding realistic expectations, and towards critical review of the available evidence.</p> <p>Parents and clinicians can refer to the Peninsula Cerebra Research Unit (PENCRU) evidence</p>

their child's functioning, and/or cause harm.	NICE CP Quality Standards Recommendations	<p>summaries, available on their website (http://www.pencru.org/).</p> <p>Other helpful websites to signpost include: Hemihelp: www.hemihelp.org.uk Contact a Family: www.contact.org.uk Whizz Kids: www.whizz-kidz.org.uk CP Sport: www.cpsport.org SCOPE: www.scope.org.uk British Paralympics Association www.parasport.org.uk English Federation of Disability Sport www.efds.co.uk</p>
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Self-Assessment Questions:

- 1) A five year old boy with bilateral CP GMFCS III is referred for tone management. He was born at 27 weeks gestation and his MRI shows peri-ventricular leukomalacia. Which of the following interventions may be considered?
 - a. A therapy programme to include strengthening
 - b. Baclofen medication
 - c. Targeted botulinum toxin injections
 - d. Deep brain stimulation
 - e. Selective dorsal rhizotomy
- 2) A three year old girl is referred for assessment and tone management. She was born at term by emergency lower segment caesarian section due to poor CTG, and developed perinatal hypoxic ischaemic encephalopathy requiring cooling. She presents with a pattern of bilateral cerebral palsy, GMFCS IV with mixed spasticity and dystonia. Which of the following statements are true?
 - a. Hip surveillance x-ray is required if not previously done.
 - b. Detailed visual assessment is recommended
 - c. MRI scan is mandatory
 - d. The clinician should reassure the family that she will be able to walk independently in future
 - e. Medication such as trihexyphenidyl may be beneficial
- 3) A teenager (age 17) who has CP: GMFCS V is referred with ongoing painful dystonia. He has had previous bilateral hip surgery. Please indicate which interventions should be considered:
 - a. Treatment for constipation
 - b. Targeted Botulinum toxin injections
 - c. Re-referral to orthopaedics
 - d. Selective dorsal rhizotomy
 - e. Adding dantrolene to his medications
- 4) A three year old boy with CP: GMFCS V, mixed spasticity and dystonia, is referred for recurrent chest infections. Which of the following statements are true?
 - a. Speech and language therapy assessment of feeding is recommended.
 - b. A normal videofluoroscopy eliminates the possibility of recurrent aspiration.
 - c. Secretion management may improve if trihexyphenidyl is used as an anti-dystonic medication.
 - d. Neuromuscular scoliosis may be causing a pattern of restrictive reduced pulmonary function.
 - e. Parents should be advised that he should not be enrolled into nursery as he may catch more infections.
- 5) An eleven year old girl with CP: GMFCS III, predominant lower limb spasticity, has just started mainstream secondary school. Which of the following statements are appropriate for her education, health and care plan.
 - a. She should have access to both her k-walker and a wheelchair at school
 - b. She should not participate in PE with her peers
 - c. Additional time may be required in moving between lessons

- d. She will require input from physiotherapy and occupational therapy throughout her secondary school years.
- e. She may require additional time to complete exams.

Answers:

- 1) A,B,C, E
- 2) A,B, E
- 3) A,B,C
- 4) A,C,D
- 5) A,C,D,E